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NCHSR program note

NATIONAL CENTER FOR HEALTH SERVICES RESEARCH
AND HEALTH CARE TECHNOLOGY ASSESSMENT
18-12 Parklawn Bldg. ■ Rockville, MD 20857 ■ 301/443-4100

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Health Services Research on HIV-Related Illnesses

The National Center for Health Services Research and Health Care Technology Assessment (NCHSR) is the principal source of Federal support for research on problems associated with the quality, cost, organization, financing, and delivery of health services in the United States. Much of this research is carried out through contracts and grants with researchers at universities, medical schools, and nonprofit institutions. Policy research and analysis also are undertaken by NCHSR staff.

Since 1987, NCHSR's research program has included issues related to the delivery of health care to individuals with AIDS and other illnesses related to the human immunodeficiency virus (HIV). The Center's HIV funding is expected to increase to approximately $9 million in fiscal year 1990. A hallmark of NCHSR's efforts in this area has been coordination with other Federal agencies, including the Centers for Disease Control, the National AIDS Program Office, the Health Resources and Services Administration, and the Health Care Financing Administration. The result has been a health services research agenda that is responsive to questions identified as critical by the Department of Health and Human Services.

A variety of issues related to HIV illnesses are being explored by NCHSR-supported researchers and staff. Descriptions of projects currently underway are provided below. Additional information may be obtained from the Publications and Information Branch, NCHSR, Parklawn Building, Room 18-12, Rockville, MD 20857; 301/443-4100.

Extramural Research

The Division of Extramural Research supports competitively awarded grant and contract health services research on various HIV-related issues. New research is encouraged on the costs and financing of care, the cost effectiveness of alternative services and organizational strategies, the quality of care, access and barriers to care, health status measures and information systems, provider issues,

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health systems analysis, and methodological development. Extramural projects are described below:

AIDS and Insurance: The Experience of a High-Risk Cohort. Nancy E. Kass, Johns Hopkins University. Grant HS 6108. This doctoral dissertation grant will survey gay and bisexual men who voluntarily participate in the Baltimore and Los Angeles chapters of the Multicenter AIDS Cohort Study, which is being funded by the National Institutes of Health. The research addresses issues of access to insurance by examining the relationships of HIV testing, antibody status, and symptom status to the experiences of respondents in applying for health, life, or disability insurance over the past five years, and their current insurance coverage. Expected completion: Summer 1989.

AIDS and Other Patients' Use of Intensive Care Unit Technologies. Robert Zussman, Columbia University. Grant HS 5548. Data from intensive care units in 2 States will be employed to examine the ways in which decisions are made to use elaborate and expensive technologies. The study will focus on the process by which decisions are made and on their outcomes, with attention to the treatment of AIDS patients and others who pose difficult social and ethical problems. Of particular interest is the role of cost factors in the decisionmaking process. Expected completion: Summer 1989.

AIDS Cost and Service Utilization Survey. This planned research activity will collect and process prospective, longitudinal data on medical and social service utilization, cost, and financing. It will be based on patient interviews and provider medical and billing records collected over an 18-month period. An attempt will be made to gather uniform data from diverse provider sites and geographic locations in order to reflect variations in patient characteristics and treatment regimens. The resulting database, which will be made available to the public, will capture total resource utilization across the entire range of HIV illnesses. This research effort will be conducted under a contract to be awarded in fiscal year 1989.

Costs of Health Services for HIV-Infected Individuals. Andrew J. Hogan, Michigan State University. Grant HS 6260. Using Medicaid records and some private health insurance data, this project will study use and cost of services for HIV-related illnesses in Michigan between January 1984 and March 1989. Hypotheses focus on differences in use and cost by risk group and sex, on the impact of AZT on average monthly Medicaid payments, and on apparent underutilization of services by some AIDS patients. Expected completion: Summer 1990.

Cost of Treatment of Intravenous Drug Users with AIDS. Julia Hidalgo, Department of Health and Mental Hygiene, State of Maryland. Grant HS 6185. Using Maryland's Statewide AIDS information system, this study will identify characteristics of intravenous drug users with AIDS, study the use and costs of health care services they receive, the fiscal impact of their care on Medicaid and other public programs, and the level of uncompensated hospital costs. Results will be useful for researchers, policymakers, and other States in developing AIDS information systems. Expected completion: Winter 1989.

Developing Tools to Study Resource Consumption in AIDS. Sankey V. Williams, University of Pennsylvania. Grant HS 6230. This pilot project will develop methods that use computerized hospital data reporting systems to identify AIDS patients and improve understanding of the costs of care and patterns of resources use for AIDS patients. Discharge data from Philadelphia's 5 medical school teaching hospitals will be studied for a 30-month period. Resource consumption patterns within and between hospitals will be compared. Expected completion: Fall 1989.

Financing Treatment Costs for Intravenous Drug Abusers with AIDS. Anthony H. Pascal, Rand Corporation. Grant HS 6130. Based on a random sample of AIDS patients affiliated with a New York hospital, data will be collected to assess the cost burden of treatment for a panel of 50 intravenous drug abusers. Data on costs, payments, patient economic variables, and service utilization will be used to construct patient longitudinal profiles. Expected completion: Winter 1989.

Health Services Research Methodology: A Focus on AIDS. Lee Sechrest, University of Arizona. Grant HS 5306. This conference, held in June 1988 in Tucson, AZ, highlighted alternative approaches for collecting and analyzing medical, financial, and socioeconomic data related to AIDS. Conference participants included health services researchers

and policy analysts. Proceedings of the conference will be published by NCHSR in Summer 1989.

Improving the Accuracy of Transfusion Decision-making. Jerome Avorn, Beth Israel Hospital, Boston. Grant HS 5300. This is a multicenter, randomized, controlled trial of an educational intervention designed to improve the cost effectiveness and clinical appropriateness of blood product utilization. It measures the effect of the intervention on the use of blood products and identifies patient and physician characteristics that enhance or impede the intervention's effect. Clinical appropriateness is defined in terms of reduced risk of transmitting diseases, including hepatitis and AIDS. Expected completion: Fall 1990.

Living Wills for Primary Care, AIDS, and Cancer Patients. John D. Stoeckle, Massachusetts General Hospital, Boston. Grant HS 6120. Three groups of patients–those seen in primary care physician practices, patients with AIDS, and patients on a telephone registry–will be interviewed to obtain information about the "durability" of their positions on living wills. Descriptive and analytic information will be used to tailor predrafted living will forms to better meet the needs of patients whose situation and treatment preferences might change. Expected completion: Fall 1990.

Medical Care Costs of AIDS Patients in San Francisco. Anne A. Scitovsky, Palo Alto (CA) Medical Foundation/Research Institute. Grant HS 5916. This study prospectively examined treatment and cost variations for AIDS patients in the San Francisco area. Comparisons were made among patients receiving care in a public hospital, an HMO, and from physicians in the community. Preliminary findings indicate that those treated at the community hospital had higher inpatient utilization and higher costs than patients in the other settings. Patients of community physicians had the highest utilization of counseling services. Overall, outpatient care accounted for approximately 30 percent of total personal medical expenditures, which is a larger share than found in previous studies. Expected completion: Spring 1989.

Modeling Methodology for Projecting the AIDS Epidemic. Marcello Pagano, Harvard University. Grant HS 6183. The researchers will develop a statistical simulation model for studying the progression and spread of AIDS, to permit predictions of the epidemic's future course, and to assess the impact of potential interventions. Based on express time transitions as a stochastic progression, the model will incorporate uncertainty about model parameters. Expected completion: Winter 1990.

The New York State Response to AIDS. W. Henry Lambright, Syracuse Research Corporation. Grant HS 6184. New York State's emergency response to AIDS will be studied, especially the work of the State's AIDS Institute. The focus will be on the coordinating role of the Institute and its regional outreach organizations. Identification of factors that have led to success and to problems in coping with AIDS in New York will be of interest to other States and Federal policymakers. Expected completion: Summer 1990.

Projecting the Costs of AIDS/ARC in the United States. Joel Hay, The Hoover Institution, Stanford University. Grant HS 6092. This research is directed toward the development of a model for projecting AIDS- and ARC-related costs that can be easily modified as new epidemiological information and treatments become available. Using the Medi-Cal AIDS patient database and data for 2 other regions, the researchers will refine and validate results of an earlier study. The model will permit estimation of lifetime costs per patient based on medical diagnosis and treatment decision tree algorithms. Expected completion: Fall 1989.

Prospects for Caring for Persons with AIDS in Nursing Homes: Perspectives of Current Residents and Policy Implications. Rosalie Kane, University of Minnesota. Contract No. 282-87-0049. This project will explore the issues surrounding admission of persons with AIDS to nursing homes in Minnesota. The researchers will interview key informants and conduct a series of focus groups with nursing home residents. The report will address policy implications, including cost and quality of care, and will develop a research agenda related to AIDS care in nursing homes. Expected completion: Summer 1989.

The Quality of Care in AIDS: Pneumocystis Carinii Pneumonia. David E. Kanouse, Rand Corporation.

Grant HS 6016. This project will examine the impact of patient characteristics, disease, and processes of care on clinical outcomes for AIDS patients and develop predictors of clinical outcomes. Data are based on hospital records of 600 newly diagnosed AIDS patients in Southern California with an initial episode of *pneumocystis carinii* pneumonia. Expected completion: Summer 1990.

Research Agenda on the Community-Based Care of Persons with AIDS. Joseph M. Keenan, University of Minnesota. Grant HS 6224. This grant is to support a conference on research problems and issues related to home- and community-based care for AIDS patients. The conference will identify and prioritize research issues related to appropriate care settings, quality of care, cost, health care policy, and the impact of both lay and professional caregivers. The conference will be held August 14-16, 1989 in Minneapolis.

U.S. Hospital AIDS Survey: 1987. Dennis P. Andrulis, National Public Health and Hospitals Institute. Grant HS 6129. A survey will be conducted in more than 600 hospitals to assess the financial and programmatic impact of AIDS on U.S. hospitals and to permit comparisons with 1985 data. Variables will include demographic characteristics of the patient populations, financing of care, and types of services provided. The 1987 survey will include a sample of pediatric cases and a study of costs related to the use of AZT. Analysis will focus on differences due to geographic location, hospital type, and changes over time. Expected completion: Fall 1989.

Variability in "No Code" Orders Among Very Ill Patients. Bernard Lo, University of California at San Francisco. Grant HS 5791. This study examines whether physicians write "Do Not Resuscitate" (DNR) orders more frequently for patients with AIDS and metastatic cancer than for those with other life-threatening conditions. Data were collected at three teaching hospitals employing a retrospective cohort design. Patients who met the diagnostic criteria for AIDS, nonresectable non-small cell lung cancer, cirrhosis with esophageal varices, or severe congestive heart failure with coronary artery disease were consecutively enrolled. Preliminary results reveal significantly higher rates of DNR orders for AIDS and cancer patients, even when controlling for differences in functional and mental status, reason for hospital admission, and severity of illness. Expected completion: Summer 1989.

Variation in Cost of AIDS Related to Gender and Risk Status. George R. Seage, Boston Department of Health and Hospitals. Grant HS 6150. This study will obtain data for the State of Massachusetts on the cost and utilization of inpatient services by all women and intravenous drug users diagnosed with AIDS from January 1987 to January 1989. Estimates will be made of costs per patient, controlling for stage of disease, site of hospitalization, and socioeconomic status. These data will be compared with data for a sample of male homosexuals and bisexuals diagnosed during the same period. Expected completion: Spring 1990.

Intramural Research

The Hospital Studies Program is one of three major areas of policy research and analysis in the Division of Intramural Research. This program focuses on questions relating to the delivery of health care in short-term general hospitals in the United States. The various research studies undertaken by this program depend on two large data bases that have been developed over the past decade to facilitate hospital-related policy research. One data base, from the Hospital Cost and Utilization Project (HCUP), contains information on a sample of more than 400 hospitals. Included are summary abstracts on all patient discharges between 1970 and 1987, the characteristics of the institutions and the markets in which they operate, and the background of the medical staff. The second data base employed by this program contains data on all patients discharged from short-term general hospitals in Maryland, New York, and Massachusetts and on the characteristics of those facilities.

Because of their size, these data sets provide the means to study even very rare medical events. Both data sets are being employed to study patients hospitalized for AIDS. For example, the relatively large number of AIDS cases included in the New York State data has provided information used to stage hospitalized AIDS patients by illness severity. Such staging is essential to studies that compare different therapeutic approaches to treating these patients or that compare costs of treatment across different hospitals or regions of the country. These data also have been used to examine the financing of

care for this costly illness. They will be used in future studies of the epidemiology of AIDS, the variations in patterns of hospital treatments, and the factors responsible for differences among hospitals with respect to the cost of diagnosis and treatment.

State and Local User Liaison Program

NCHSR's State and Local User Liaison Program conducts workshops on the impact of the AIDS epidemic on State governments. The workshops are created specifically to meet the information needs of State legislators, senior legislative staff, elected county officials, and State executives who are not involved full time with health issues but have major responsibilities for health policies and programs. These 3-day meetings focus on such topics as the clinical nature of AIDS; the epidemiologic aspects of its spread; the technical aspects of current testing technologies; research findings on various population groups' awareness of their risk for AIDS and the impact educational efforts can have on reducing high-risk behavior; estimates of current and projected AIDS-related treatment costs; the unique challenges AIDS has placed on the health care delivery system; the roles of State governments in financing care for AIDS patients through Medicaid programs and the regulation of private health insurance activities; and a variety of policy issues related to confidentiality, discrimination, and personal control measures. The workshops also cover health services research activities that State governments can sponsor to better understand the current and future nature of the AIDS problem in their jurisdictions and to assess the effectiveness of different programs and policies in controlling the disease.

Selected NCHSR Publications on HIV-Related Illnesses

The following publications on AIDS and HIV-related illnesses have been produced with NCHSR support. They are numbered consecutively and listed in four subject categories: conference proceedings, journal articles and publications, research protocols, and general information. Single copies are available without charge. To order, please circle the corresponding number on the order form at the back of this brochure for each publication you want. Then send the completed order form to the Publications and Information Branch, NCHSR, Parklawn Building, Room 18-12, 5600 Fishers Lane, Rockville, MD 20857. Questions? Please call us at 301/443-4100.

Conference Proceedings

1. *Health Services Research Methodology: A Focus on AIDS* (in process). Proceedings of a conference sponsored by the National Center for Health Services Research and Health Care Technology Assessment, June 2-4, 1988. L. Sechrest, H. Freeman, and A. Mulley, Eds. This conference presented new methods for dealing with the complex and unique methological issues involved in collecting and analyzing data on AIDS and HIV-related illnesses. Complete conference proceedings, including presentations, discussions, and keynote addresses, are available in a single volume. Main presentations were:

- Measurement Models for Rating and Comparing Risks: The Context of AIDS, by Robyn Dawes, Ph.D., Carnegie Mellon University
- Evaluation of Prognosis and Transitions: General Strategic Principles and Applications in AIDS, by Alvin Feinstein, M.D., Yale University
- The Costs of AIDS: Alternative Methodological Approaches, by Mark Thompson, Ph.D., Equity Resources Group
- Some Limitations of Longitudinal and Cohort Designs in Social and Behavioral Research, by Norvall D. Glenn, Ph.D., University of Texas at Austin
- Critical Multiplism: A Research Strategy and its Attendant Tactics, by William R. Shadish, Jr., Ph.D., Memphis State University
- Resolving Privacy Problems in AIDS Research: A Primer, by Robert Boruch, Ph.D., Northwestern University
- Statistical Analysis of Survival Data, with Applications to the AIDS Epidemic, by Stephen Lagakos, Ph.D., Harvard University
- The Analysis of Randomized and Nonrandomized AIDS Treatment Trials Using a New Approach to Causal Inference in Longitudinal Studies, by James Robins, Ph.D., Harvard University

2-12. *New Perspectives on HIV-Related Illnesses: Progress in Health Services Research* (in process). Proceedings of a conference sponsored by the National Center for Health Services Research and Health Care Technology Assessment, May 17–19,

1989, in Miami, FL. The conference was the first to focus on the contributions of health services research to the resolution of problems associated with the HIV epidemic. Complete conference proceedings (2), including keynote addresses, main presentations, and discussions, are in process and will be available as a single volume. The following presentations currently are available as individual monographs:

3. Past Lessons and Future Directions: The Economics of Health Services Delivery for HIV-Related Illnesses, by Anne A. Scitovsky, M.A., Palo Alto Medical Foundation/Research Institute.

4. The Costs and Financing of Care for AIDS Patients: Results of a Cohort Study in Los Angeles, by Anthony Pascal, Ph.D., Rand Corporation, and others.

5. Collecting Statewide Data on HIV Costs and Financing: Pitfalls and Payoffs, by Julia Hidalgo, Sc.D., AIDS Administration, Department of Health and Mental Hygiene, State of Maryland.

6. Hospital Trends and the Financing of Medical Care for AIDS Patients, by Dennis P. Andrulis, Ph.D., and Virginia Beers Weslowski, M.P.A., National Public Health and Hospital Institute.

7. Projecting the Medical Costs of HIV/AIDS: An Update with Focus on Epidemiology, by Joel Hay, Ph.D., The Hoover Institution.

8. AIDS Severity-of-Illness Classification Systems for Health Services Research, by Barbara J. Turner, M.D., Jefferson Medical College, and Judy K. Ball, Ph.D., NCHSR.

9. Modeling the Impact of the AIDS/HIV Epidemic on State Medicaid Programs, by Linda T. Bilheimer, Ph.D., Mathematica Policy Research, Inc.

10. Perspectives on a Continuum of Care for Persons with HIV Illnesses, by A.E. Benjamin, Ph.D., University of California at San Francisco.

11. Quality of Care and HIV-Related Illnesses, by David E. Kanouse, Ph.D., Rand Corporation; W. Christopher Matthews, M.D., University of California, San Diego; and Charles L. Bennett, M.D., Rand Corporation and UCLA School of Medicine.

12. Clinical Ethics and HIV-Related Illnesses: Issues in Treatment and Health Services Research, by Bernard Lo, M.D., University of California at San Francisco.

Journal Articles and Publications

13. Ball, Judy K., Joyce V. Kelly, and Barbara J. Turner. Distribution of the financial burden for AIDS hospitalizations among third-party payers in New York. Presented at the Fourth International Conference on AIDS, Stockholm, Sweden, June 12–16, 1988.

14. Hellinger, Fred J. (1988, May-June). Forecasting the personal medical costs of AIDS from 1988 through 1991. *Public Health Reports 103(3)*, pp. 309–19.

15. Hellinger, Fred J. (1988, Winter). National forecasts of the medical care costs of AIDS: 1988-1992. *Inquiry 25(4)*, pp. 469–84.

16. Kelly, Joyce V., Judy K. Ball, and Barbara J. Turner. Severity of illness in use of hospital resources by AIDS patients. Presented at the Fourth International Conference on AIDS, Stockholm, Sweden, June 12–16, 1988.

17. NCHSR Staff. (1988, September). *Selected Bibliography on AIDS for Health Services Research.* A 100-page bibliography with nearly 300 annotated citations for articles related to AIDS service delivery issues for articles published between August 1987 and August 1988.

18. Turner, Barbara J., Joyce V. Kelly, and Judy K. Ball. (1989, April). A severity classification system for AIDS hospitalizations. *Medical Care* 27(4), pp. 423–37.

Research Protocols

Developed under NCHSR contract No. 282–87–0050, these six protocols address research issues and methods to assist investigators in developing studies concerning the use and costs of health services by persons with AIDS and HIV-related illnesses. The protocols are:

19. *Estimating the Use and Cost of Medical, Social, and Support Services for Persons with AIDS and ARC.*

20. *Comparisons of the Cost-Effectiveness of Various Treatment Modalities.*

21. *Comparisons of the Cost Effectiveness of Alternative Models for Organizing Services for Persons with AIDS.*

22. *Comparing the Cost of AIDS to the Cost of Other Illnesses.*

23. *Estimating the Demand, Supply, and National Costs of HIV Testing.*

24. *HIV-Related Training Needs, Programs, and Costs.*

General NCHSR Program Information

25. *AIDS Health Services Research.* May 1989. A brief description of NCHSR-funded grants and contracts and inhouse research on AIDS and HIV-related illnesses. Included are listings of recently completed projects, those in progress, and resulting publications. (Also reproduced at the front of this brochure.)

26. *HIV-Related Illnesses: Topics for Health Services Research.* October 1988. An 11-page overview of NCHSR's research interests in HIV-related illnesses and possible topics for investigator-initiated research.

27. *National Center for Health Services Research and Health Care Technology Assessment: Functions and Program.* (1988). A four-page description of NCHSR's organizational components and their functions.

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Publications Ordering Form

Single copies of the publications listed in this brochure are available without charge. To order, fill in your name and address and circle the number of each publication you want. Send the completed form to the National Center for Health Services Research and Health Care Technology Assessment, Publications and Information Branch, Parklawn Bldg., Rm. 18-12, Rockville, MD 20857.

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Publication Numbers

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